

Cancer Prevalence and Survivorship Issues: Analyses of the 1992 National Health Interview Survey

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Background/Methods: Relatively little is known about the size and makeup of the growing population of cancer survivors or about the social implications of a diagnosis of cancer. To explore these issues, we analyzed cancer survivorship information from the 1992 National Health Interview Survey (NHIS), and resulting cancer prevalence estimates were compared with those derived from cancer registry data. **Results:** According to the NHIS, there were an estimated 7.2 million adult survivors of cancer—excluding non-melanoma skin cancer—in 1992, representing 3.9% of the U.S. adult population. Comparisons with prevalence estimates from cancer registry data suggest that cancer is underreported in the NHIS. Nearly three fifths (58.0%) of cancer survivors self-identified on the NHIS reported that their cancer was first detected when they noticed something wrong and went to a doctor. The majority (55.7%) of cancer survivors had obtained a second opinion or multiple opinions regarding their treatment. Most (58.0%) had received patient educational materials from a health care provider. However, relatively few had received counseling or participated in support groups (14.2%), contacted cancer organizations after their diagnosis (10.9%), or participated in a research study or clinical trial as part of their cancer treatment (4.7%). One ninth (10.7%) of the survivors had been denied health or life insurance coverage because of their cancer. Nearly one fifth (18.2%) of the cancer survivors who worked before or after their cancer was diagnosed experienced employment problems because of their cancer. **Conclusions:** While cancer appears to be underreported on the 1992 NHIS, the survey provides valuable information about the medical, insurance, and employment experience of cancer survivors selected from a nationally representative sample of

U.S. households. [J Natl Cancer Inst 1999;91:1480–6]

As more people seek effective cancer-screening tests, have their cancer detected early, and benefit from advances in cancer treatment, the number of cancer survivors can be expected to grow. Relatively little is known about the size and makeup of this population or about the medical care experience of and social implications for patients who have had a diagnosis of cancer. In 1992, a nationally representative sample of individuals was interviewed as part of the National Health Interview Survey (NHIS). Those reporting a diagnosis of cancer at some time in their past were asked about their experiences with cancer.

METHODS

Data Sources

The NHIS is a principal source of information on the health of the U.S. noninstitutionalized, civilian population (1). The NHIS is conducted by the National Center for Health Statistics, Hyattsville, MD, and provides national data on the incidence of illness and accidental injuries, the prevalence of chronic conditions and impairments, the extent of disability, and the utilization of health care services. The 1992 NHIS included two cancer supplements, the Cancer Control Supplement and the Cancer Epidemiology Supplement, each of which included a Cancer Survivorship Section (2). In each of the 49 401 households selected for interviews, a sample adult respondent (≥ 18 years old) was selected to complete the cancer survivorship questions. Because of budgetary constraints, cancer supplement interviews were stopped during the third quarter of the field period, with 24 040 NHIS respondents having completed the Cancer Survivorship Section. The overall response rates for the Cancer Control and Cancer Epidemiology Supplements were 87% and 86%, respectively.

For purposes of the NHIS, cancer survivors include respondents who reported ever having a diagnosis of cancer, regardless of whether they currently had symptoms of cancer. A total of 1553 respondents reported that a doctor had told them that they had cancer. These respondents were asked how many different kinds of cancer they had had, the types of cancer they had, when the first cancer was diagnosed and at what age, and how the cancer was first detected. When more than one cancer had been diagnosed, information on the most recently diagnosed cancer was also reported (i.e., type of cancer, year of diagnosis, and age at diagnosis). A total of 1519 respondents (98%) identified the kind of cancer they had. Excluding nonmelanoma skin cancer, there were 1020 cancer survivors identified. Of these, 656 individuals had been diagnosed with cancer in the last 10 years (either a primary or a subsequent cancer) and were asked to provide information on their experiences around the time of diagnosis and whether they had subsequent problems with insurance coverage and employment.

For the assessment of the validity of survey-

reported cancer prevalence, national estimates of cancer prevalence were calculated on the basis of Connecticut Tumor Registry prevalence rates, age adjusted by sex to the 1992 U.S. population with the use of NHIS weights (adults only). In existence since 1935, the Connecticut Tumor Registry is the oldest population-based cancer registry in the United States and has sufficient length of follow-up of reported cases to generate accurate prevalence estimates (3). To make the registry-based estimates comparable to self-reported cancers, we included *in situ* diseases of the breast and cervix in the prevalence estimates [special tabulations prepared by David Annett, Information Management Services, Silver Spring, MD, October 1998; (3)].

Statistical Analyses

Descriptive statistics and logistic-regression models are presented to assess whether cancer survivors' characteristics are associated with six dichotomous outcomes of interest: receipt of a second opinion, receipt of counseling/participation in a support group, receipt of patient educational materials, contact with cancer organizations, participation in clinical research, and cancer-related problems in employment. The NHIS has a complex survey design involving stratification, clustering, and disproportionate sampling. All proportions and population counts presented are weighted to provide national estimates. Variance estimates for proportions and logistic-regression model odds ratios (ORs) were calculated by use of the Taylor series approximation technique, taking into account the complex design of the survey [Stata Statistical Software (4)]. All *P* values are two-sided; if less than .05, they are considered statistically significant.

RESULTS

Prevalence of Self-Reported Cancer

In 1992, an estimated 11 million Americans, or 6.1% of the total adult population, had ever had cancer according to the NHIS. If skin cancers other than melanoma are excluded, there were an estimated 7.2 million Americans with a history of a cancer diagnosis, representing 3.9% of the U.S. population (Table 1, A).

Comparisons of NHIS and cancer registry prevalence estimates suggest that cancer was underreported in the NHIS and that men were less likely than women to report cancer (Table 1, B). For men, the survey's estimate of overall cancer prevalence was 20.2% lower than the cancer

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Table 1. Self-reported cancer prevalence among U.S. adults, National Health Interview Survey (NHIS), 1992

A) Numbers of adults who report ever having had cancer diagnosed (excluding superficial skin cancer) and cancer prevalence (per 100 000), by site or type of cancer and by sex, United States, 1992*							
	NHIS sample size	No. of cases estimated, rounded to nearest 1000			Prevalence rate per 100 000 (95% confidence interval)		
		Total	Male	Female	Total	Male	Female
Total	1020	7 188 000	2 171 000	5 016 000	3886 (3590–4182)	2463 (2129–2797)	5181 (4710–5653)
Site or type of cancer†							
Cervix, uterus, other female genital organs	307	1 997 000	—	1 997 000	1079 (942–1217)	—	2062 (1798–2327)
Breast	213	1 467 000	—	1 467 000	793 (669–917)	—	1515 (1278–1752)
Prostate, testes, other male genital organs	84	685 000	685 000	—	371 (274–467)	777 (575–980)	—
Colorectal	95	657 000	314 000	344 000	355 (269–441)	356 (234–478)	355 (227–482)
Leukemia, Hodgkin's disease	48	373 000	204 000	169 000	202 (138–265)	232 (120–343)	174 (100–248)
Larynx, trachea, bronchus, lung	43	314 000	132 000	182 000	170 (111–229)	150 (70–229)	188 (100–276)
Skin, melanoma	38	285 000	144 000	141 000	154 (103–205)	164 (80–248)	145 (82–209)
Other specified site	192	1 409 000	691 000	718 000	762 (633–890)	784 (585–984)	741 (596–886)

B) Comparison of cancer prevalence among adults, as estimated by the NHIS and cancer registry data, by site or type of cancer and by sex, United States, 1992

	Prevalence, per 100 000				% difference in prevalence, NHIS relative to cancer registry	
	NHIS		Cancer registry‡		Male	Female
	Male	Female	Male	Female		
Total	2463	5181	3086	5338	–20.2	–2.9
Site or type of cancer†						
Cervix, uterus, other female genital organs	—	2062	—	1950	—	5.7
Breast	—	1515	—	1912	—	–20.8
Prostate, testes, other male genital organs	777	—	912	—	–14.8	—
Colorectal	356	355	596	563	–40.3	–36.9
Leukemia, Hodgkin's disease	232	174	291	246	–20.2	–29.2
Larynx, trachea, bronchus, lung	150	188	326	185	–54.0	1.6
Skin, melanoma	164	145	205	204	–20.0	–28.9
Other specified site	784	741				

*Numbers do not add up because of rounding error.

†International Classification of Diseases, 9th Revision (ICD-9), codes for cancers are as follows: skin, melanoma (172); cervix, uterus, other female genital organs (179, 180, 181, 182, 183, 184); female breast (174); prostate, testes, other male genital organs (185, 186, 187); colorectal (153, 154); leukemia, Hodgkin's disease (201, 202, 203, 208); larynx, trachea, bronchus, lung (161, 162); and other reported specified site (140, 142, 145, 149, 150, 151, 152, 156, 157, 159, 170, 171, 188, 189, 190, 191, 193, 195, 196, 199) (17). When multiple cancers were reported, type of cancer refers to the first cancer diagnosed. ICD-9 codes not listed were not reported on the NHIS.

‡National estimates of cancer prevalence are based on Connecticut Tumor Registry rates, age adjusted by sex to the 1992 U.S. population with the use of NHIS weights, adults only. For comparability with self-reported cancers, *in situ* diseases of the breast and cervix were included. Registry-based site- or type-specific prevalence rates do not add to the total because, when multiple cancers were reported, each was included in site- or type-specific prevalence rates.

registry estimate; in contrast, for women, the degree of underreporting was only 2.9%. The NHIS prevalence estimates appear to be especially low for cancers of the larynx, trachea, bronchus, and lung among men (54.0% lower than cancer registry estimates) and for colorectal cancer among both men and women (40.3% and 36.8% lower, respectively) (Table 1, B). Female genital cancers are slightly overrepresented by self-report; survey estimates were 5.7% higher than registry data.

Characteristics of Cancer Survivors

According to the 1992 NHIS, the leading types of self-reported cancer among all cancer survivors are female reproductive cancers (e.g., uterine, including cervical) (27.8%), female breast cancer

(20.4%), prostate and male reproductive organ cancers (9.5%), and colorectal cancer (9.1%) (Table 2). Cancer survivors are predominantly women (69.8%), and nearly half (46.2%) are 65 years old or older. More than three quarters (76.4%) of cancer survivors were first diagnosed with cancer at age 35 years or older; the majority (52.4%) were diagnosed at ages 35–64 years. Most cancer survivors (63.3%) have lived 5 or more years following their diagnosis, and nearly one tenth (9.9%) have survived for more than 25 years. Racial and ethnic minority groups are underrepresented among cancer survivors (11.7% of those with a history of cancer versus 22.6% of those without a history of cancer are Hispanic, Black, or other race). This result suggests

poorer survival but could also be related to differential reporting or variation in incidence rates. More than one third (36.5%) of cancer survivors rate their health as excellent or very good. Fewer than one third (32.2%) of survivors rate their health as fair or poor.

Detection of Initial Cancer

Most individuals reporting cancer (58.0%) said that their cancer was first detected when they noticed something wrong and went to a doctor. Nearly one third (29.8%) had no symptoms and had the cancer detected during a routine checkup. The remaining 12.2% had their cancer detected in some other way. Cancers for which there are effective screening tests should be more likely to be de-

Table 2. Numbers of adult cancer survivors and their distribution by site or type of cancer, age at interview, age at diagnosis, years since diagnosis, sex, race/ethnicity, and self-reported health status, National Health Interview Survey (NHIS), United States, 1992*

	Sample size	Estimated No.	% of total (95% confidence interval)
Total	1020	7 187 600	100.0
Site or type of cancer†			
Cervix, uterus, other female genital organs	307	1 996 800	27.8 (24.7–30.9)
Breast	213	1 466 800	20.4 (17.6–23.2)
Prostate, testes, other male genital organs	84	685 500	9.5 (7.2–11.9)
Colorectal	95	657 400	9.1 (7.0–11.3)
Leukemia, Hodgkin's disease	48	373 200	5.2 (3.6–6.7)
Larynx, trachea, bronchus, lung	43	314 100	4.4 (2.9–5.9)
Skin, melanoma	38	284 900	4.0 (2.7–5.2)
Other specified site	192	1 408 900	19.6 (16.7–22.5)
Age at interview, y			
18–24	28	209 600	2.9 (1.7–4.1)
25–44	199	1 377 900	19.2 (16.5–21.9)
45–64	297	2 277 700	31.7 (28.4–35.0)
65–69	121	880 600	12.2 (9.6–14.9)
70–74	128	934 300	13.0 (10.5–15.5)
≥75	247	1 507 500	21.0 (18.4–23.5)
Age at diagnosis, y			
<35	244	1 649 500	23.6 (20.4–26.8)
35–64	501	3 655 500	52.4 (48.9–55.8)
≥65	251	1 678 900	24.0 (20.8–27.3)
Years since diagnosis			
<5	357	2 639 500	36.7 (33.4–40.1)
5–10	251	1 734 700	24.1 (20.9–27.4)
11–15	142	998 600	13.9 (11.5–16.3)
16–20	96	625 500	8.7 (6.6–10.8)
21–25	66	476 700	6.6 (4.8–8.5)
26–30	35	203 700	2.8 (1.8–3.8)
≥31	73	508 900	7.1 (5.4–8.8)
Sex			
Male	266	2 171 400	30.2 (26.9–33.5)
Female	754	5 016 200	69.8 (66.5–73.1)
Race/ethnicity			
White, non-Hispanic	869	6 326 000	88.3 (86.1–90.5)
White, Hispanic	42	210 500	2.9 (1.9–4.0)
Black	90	506 500	7.1 (5.4–8.8)
Other	15	119 300	1.7 (0.6–2.7)
Self-reported health status			
Excellent	144	991 300	14.5 (11.8–17.2)
Very good	217	1 500 900	22.0 (18.8–25.1)
Good	304	2 136 900	31.3 (27.6–34.9)
Fair	191	1 355 700	19.8 (16.5–23.1)
Poor	113	851 100	12.4 (10.2–14.7)

*Some categories had missing values.

†International Classification of Diseases, 9th Revision (ICD-9), codes for cancers are as follows: skin, melanoma (172); cervix, uterus, other female genital organs (179, 180, 181, 182, 183, 184); female breast (174); prostate, testes, other male genital organs (185, 186, 187); colorectal (153, 154); leukemia, Hodgkin's disease (201, 202, 203, 208); larynx, trachea, bronchus, lung (161, 162); and other reported specified site (140, 142, 145, 149, 150, 151, 152, 156, 157, 159, 170, 171, 188, 189, 190, 191, 193, 195, 196, 199) (17). When multiple cancers were reported, type of cancer refers to the first cancer diagnosed. ICD-9 codes not listed were not reported on the NHIS.

tected through routine checkups than cancers without such tests. This appeared to be the case for cancers of the breast, cervix, and prostate but not for colorectal cancer.

Frequency of Second Opinion About Type of Treatment¹

More than half (55.7%) of the individuals with cancer reported ob-

taining a second or multiple opinions regarding their treatment (Table 3). According to multivariate analyses, characteristics associated with a statistically significant greater use of second opinion include the following (Table 4):

- Hispanic origin (relative to white, non-Hispanic) (OR = 2.8; 95% confidence interval [CI] = 1.0–7.8; *P* = .049);

- breast cancer (relative to “other cancers”) (OR = 2.1; 95% CI = 1.2–3.7); and
- residence in a noncentral city Metropolitan Statistical Area (MSA)² (relative to non-MSAs) (OR = 1.9 [95% CI = 1.1–3.0]).

Residents of the Northeast had a statistically significant lower use of second opinions (OR = 0.5; 95% CI = 0.3–0.9).

Very few (13.1%) individuals with cancer reported seeing only their internist or general practitioner for their diagnosis and treatment.

Receipt of Counseling or Participation in Support Group

Relatively few persons (14.2%) reported receiving counseling or joining a support group following their diagnosis (Table 3). Among those who did not receive counseling, most (64.1%) felt that they did not need it, 11.8% did not want it, and 9.4% did not know that it was available. Another 14.7% said that they did not get counseling for some other reason. Individuals with breast cancer were statistically significantly more likely than those with other cancers to have received counseling or to have participated in a support group (OR = 2.4; 95% CI = 1.0–5.6; *P* = .047) (Table 4). Those diagnosed with cancer recently were more than twice as likely than those diagnosed 5 or more years ago to have reported receiving counseling or joining a support group (OR = 2.6; 95% CI = 1.4–4.7) (Table 4).

Patient Education

More than half (58.0%) of those with cancer reported having received written information about their cancer or its treatment from a doctor, nurse, or social worker (Table 3). Another 7.0% did not get written information from a provider but did pick the materials up themselves. Approximately one third of cancer survivors (35.0%) reported not having received written patient information materials. According to multivariate analyses, individuals with breast cancer relative to those with other cancers (OR = 2.5; 95% CI = 1.3–4.9) and those under age 65 years relative to older individuals (<35 years of age, OR = 3.9 [95% CI = 2.0–7.6]; 35–64 years of age, OR = 2.6 [95% CI = 1.5–4.4]) were more than twice as

Table 3. Proportion of cancer survivors who received a second opinion, counseling/support services, or patient educational materials, who contacted a cancer organization, who participated in clinical research, or who experienced problems in employment, by site or type of cancer, sex, race/ethnicity, age at diagnosis, years since diagnosis, educational attainment, poverty level income, region of residence, and metropolitan residence, National Health Interview Survey (NHIS), United States, 1992*

Characteristic	Receipt of second opinion (n = 659), % (95% CI)	Receipt of counseling/ support services (n = 659), % (95% CI)	Receipt of patient educational materials (n = 650), % (95% CI)	Contacted cancer organization (n = 662), % (95% CI)	Participated in clinical research (n = 653), % (95% CI)	Experienced problems in employment (n = 291), % (95% CI)
Total	55.7 (51.1–60.2)	14.2 (11.5–17.5)	58.0 (53.7–62.3)	10.9 (8.3–14.2)	4.7 (3.0–7.2)	18.2 (13.4–24.2)
Site or type of cancer						
Colorectal	44.6 (32.8–57.0)	—	35.6 (24.5–48.5)	—	—	—
Breast	65.9 (57.0–73.7)	26.6 (19.1–35.6)	71.7 (62.8–79.2)	19.4 (12.6–28.6)	—	24.1 (14.1–38.0)
Female reproductive	51.1 (42.0–60.2)	—	61.1 (52.0–69.5)	—	—	—
Prostate, other male reproductive	54.3 (41.6–66.4)	14.7 (8.1–24.3)	60.3 (47.8–71.7)	—	—	—
Other cancers	54.6 (45.8–63.0)	12.2 (8.2–17.8)	53.0 (44.6–61.4)	14.4 (9.4–21.5)	—	25.9 (16.4–38.4)
Sex						
Male	56.4 (48.2–64.2)	12.3 (8.2–18.2)	51.9 (44.2–59.4)	8.5 (5.2–13.5)	5.7 (2.9–10.8)	19.0 (10.6–31.5)
Female	55.4 (49.8–60.9)	15.3 (11.8–19.5)	61.2 (56.0–66.1)	12.1 (8.7–16.7)	4.1 (2.3–7.2)	17.9 (12.7–24.7)
Race/ethnicity†						
White, non-Hispanic	55.4 (50.6–60.1)	14.0 (11.1–17.6)	59.6 (54.9–64.2)	11.0 (8.3–14.3)	4.6 (2.9–7.1)	18.4 (13.3–24.9)
White, Hispanic	71.8 (49.2–87.0)	—	57.6 (34.2–78.1)	—	—	—
Black	59.4 (44.5–72.7)	—	45.5 (20.3–61.6)	—	—	—
Age at diagnosis, y						
<35	59.9 (50.5–68.6)	11.9 (7.1–19.5)	63.4 (53.9–72.0)	10.3 (5.9–17.5)	9.1 (4.7–16.8)	21.4 (13.7–31.7)
35–64	58.9 (51.9–65.5)	16.7 (12.7–21.7)	63.1 (56.3–69.4)	12.4 (9.1–16.7)	5.3 (3.0–9.2)	18.0 (11.8–26.6)
≥65	47.9 (40.5–55.3)	11.5 (7.4–17.4)	46.6 (39.4–53.9)	9.2 (5.2–15.7)	—	—
Years since diagnosis						
<5	55.2 (49.3–60.9)	16.9 (13.3–21.4)	60.7 (54.8–66.4)	13.6 (9.6–19.0)	5.4 (3.0–9.5)	15.0 (9.2–23.6)
≥5	54.5 (47.4–61.4)	8.2 (5.4–12.1)	54.4 (47.0–61.6)	7.8 (5.2–11.7)	—	21.9 (14.7–31.3)
Educational attainment						
Less than high school	47.3 (38.5–56.2)	10.0 (6.1–16.0)	49.3 (40.2–58.5)	6.5 (3.6–11.4)	—	—
High school	54.0 (46.3–61.4)	13.7 (9.9–18.8)	61.4 (53.7–68.5)	13.4 (8.8–20.0)	—	19.4 (11.9–30.1)
Greater than high school	63.8 (56.3–70.6)	17.8 (13.3–23.5)	60.8 (53.4–67.8)	11.2 (7.8–16.0)	6.2 (3.6–10.5)	19.6 (12.6–29.2)
Poverty level income						
Above poverty level	57.1 (51.9–62.1)	14.8 (11.8–18.3)	60.5 (55.7–65.2)	11.2 (8.3–15.0)	5.2 (3.3–8.1)	19.5 (14.1–26.3)
At or below poverty level	44.5 (31.7–58.1)	—	50.7 (35.8–65.5)	—	—	—
Region of residence						
Northeast	54.1 (45.1–62.9)	14.1 (9.4–20.5)	67.3 (56.8–76.4)	10.2 (6.6–15.5)	—	—
Midwest	48.2 (39.9–56.6)	10.7 (6.7–16.6)	57.8 (49.4–65.8)	9.0 (4.8–16.0)	—	—
South	54.6 (46.5–62.5)	13.6 (9.2–19.7)	50.6 (43.5–57.7)	7.9 (4.9–12.6)	—	19.5 (11.9–30.2)
West	69.9 (60.9–77.5)	20.5 (13.1–30.5)	62.5 (52.1–71.9)	19.7 (12.2–30.3)	—	22.8 (12.9–37.1)
Metropolitan residence						
MSA, central city	58.8 (50.9–66.2)	17.9 (12.6–24.9)	63.7 (56.3–70.5)	11.4 (7.4–17.0)	8.6 (4.8–15.2)	22.2 (13.5–34.2)
MSA, noncentral city	59.0 (51.9–65.7)	14.5 (10.4–19.9)	54.4 (47.6–61.1)	13.3 (8.8–19.6)	—	16.7 (9.7–27.4)
Non-MSA	46.2 (38.4–54.0)	9.5 (6.1–14.6)	58.2 (49.9–66.0)	—	—	15.2 (8.1–26.8)

*95% CI = 95% confidence interval; — = too few cases for analysis; MSA = metropolitan statistical area.

†There are too few cases of “other” race to display separately.

likely to have received materials from their health care provider. Those diagnosed with cancer recently were more likely than those diagnosed 5 or more years ago to have received written information (OR = 1.8 [95% CI = 1.2–2.9]) (Table 4).

Almost everyone (93.6%) who obtained written materials reported that the materials were helpful. The topics covered in the materials received included the following (respondents could choose more than one category):

- General information about cancer (64.2%)

- Information about a specific type of cancer (75.1%)
- Cancer treatment options (36.3%)
- Coping with the physical side effects of cancer treatment (37.4%)
- Coping with the emotional effects of cancer (27.4%)
- Other topics (8.4%)

Contact With Cancer Organizations

Relatively few (10.9%) cancer survivors reported having contacted cancer organizations, such as the National Cancer Institute or the American Cancer Society, after their diagnosis (Table 3). Women re-

porting cervical cancer compared with those reporting other cancers were statistically significantly less likely to have made contact (OR = 0.1; 95% CI = 0.0–0.5), according to multivariate analyses (Table 4). Those diagnosed with cancer recently were much more likely than those diagnosed with cancer 5 or more years ago to have made such contact (OR = 2.6; 95% CI = 1.3–5.3).

Participation in Clinical Research

Very few cancer survivors (4.7%) reported participating in a research study or in a clinical trial as a part of their cancer

Table 4. Odds ratios (ORs) and 95% confidence intervals (CIs) associated with multivariate logistic regression models, National Health Interview Survey (NHIS), 1992

Characteristic	OR (95% CI)*			
	Receipt of second opinion (n = 538)	Receipt of counseling/ support group (n = 537)	Receipt of patient educational materials (n = 532)	Contacted cancer organization (n = 539)
Cancer				
Colorectal	0.7 (0.3–1.4)	1.2 (0.4–3.4)	0.6 (0.3–1.2)	0.3 (0.1–1.6)
Breast	†2.1 (1.2–3.7)	†2.4 (1.0–5.6)	†2.5 (1.3–4.9)	1.1 (0.5–2.4)
Female reproductive	1.0 (0.5–2.0)	0.3 (0.1–1.0)	1.2 (0.6–2.4)	†0.1 (0.0–0.5)
Prostate, other male reproductive	0.9 (0.4–1.8)	1.6 (0.6–4.9)	1.7 (0.8–3.6)	0.5 (0.1–2.2)
Other cancers	—	—	—	—
Sex				
Male	1.7 (0.9–3.3)	0.7 (0.2–1.9)	1.2 (0.6–2.1)	0.6 (0.2–1.8)
Female	—	—	—	—
Race/ethnicity				
White, non-Hispanic	—	—	—	—
White, Hispanic	†2.8 (1.0–7.8)	1.0 (0.2–4.9)	1.0 (0.4–2.9)	0.9 (0.2–5.1)
Black	1.3 (0.6–2.7)	1.4 (0.5–4.2)	0.6 (0.3–1.4)	1.0 (0.2–4.1)
Age at diagnosis, y				
<35	1.9 (1.0–3.8)	1.8 (0.7–5.0)	†3.9 (2.0–7.6)	2.0 (0.6–6.3)
35–64	1.6 (1.0–2.8)	1.7 (0.8–3.6)	†2.6 (1.5–4.4)	1.1 (0.5–2.5)
≥65	—	—	—	—
Years since diagnosis				
<5	1.1 (0.7–1.6)	†2.6 (1.4–4.7)	†1.8 (1.2–2.9)	†2.6 (1.3–5.3)
≥5	—	—	—	—
Educational attainment				
Less than high school	—	—	—	—
High school	0.9 (0.5–1.6)	1.4 (0.6–3.1)	1.5 (0.8–2.7)	2.4 (0.9–6.0)
Greater than high school	1.2 (0.7–2.3)	1.9 (0.9–4.0)	1.0 (0.5–1.8)	2.1 (0.8–5.3)
Poverty level income				
Above poverty level	1.4 (0.7–2.9)	1.0 (0.4–2.7)	1.4 (0.6–3.0)	0.6 (0.2–1.6)
At or below poverty level	—	—	—	—
Region of residence				
Northeast	†0.5 (0.3–0.9)	0.9 (0.4–2.0)	1.4 (0.6–3.0)	0.5 (0.2–1.1)
Midwest	0.6 (0.3–1.1)	0.7 (0.3–1.6)	0.9 (0.5–1.6)	0.5 (0.2–1.2)
South	0.6 (0.3–1.0)	0.7 (0.3–1.6)	0.6 (0.4–1.1)	0.4 (0.2–1.1)
West	—	—	—	—
Metropolitan residence‡				
MSA, central city	1.7 (1.0–2.9)	1.8 (0.8–3.9)	1.6 (0.9–2.9)	2.3 (0.7–7.0)
MSA, noncentral city	†1.9 (1.1–3.0)	1.2 (0.6–2.5)	0.7 (0.4–1.3)	2.8 (0.9–8.5)
Non-MSA	—	—	—	—

*— = reference category.

†Denotes significance (two-sided) at $P < .05$.

‡MSA = metropolitan statistical area.

treatment (Table 3). Therefore, the sample size was insufficient for multivariate analyses.

Change in Health or Life Insurance Coverage Because of Cancer

Roughly one in nine (10.7%) cancer survivors reported having been denied health or life insurance coverage because of cancer. Relatively few individuals (6.8%) with private health insurance that paid for all or part of their cancer treatment reported that their health insurance changed because of cancer following their diagnosis. Insurance cost increases were reported by 4.9% of cancer survivors. Very few (1.8%) reported that they were

asked to waive coverage of their cancer in order to get health insurance.

Cancer-Related Problems With Employment

Fewer than half (43.2%) of cancer survivors worked before their diagnosis was made. Nearly one quarter (24.0%) of cancer survivors were 65 years old or older at diagnosis, which may in part account for this relatively low level of employment. Individuals ($n = 291$) who worked immediately before or after their cancer was diagnosed but who were not self-employed were asked a series of questions about cancer-related employment problems. Nearly one in five (18.2%) of

these cancer survivors reported at least one of the following problems: felt that they could not take a new job because of a change in insurance related to cancer (13.2%), felt that they could not change jobs because of cancer (7.8%), faced on-the-job problems from an employer or supervisor directly related to their cancer (4.5%), refrained from applying for a new job because they did not want their medical records made public (4.4%), or were fired or laid off from their job because of their cancer (3.7%).

DISCUSSION

The 1992 NHIS estimate of cancer prevalence among adults (3886 per 100 000; 95% CI = 3590–4182) was statistically significantly higher than an earlier estimate from the 1987 NHIS (3230 per 100 000; 95% CI = 3054–3406) (5). This growth in the share of the population that has had experience with cancer could be attributable to the aging of the population, increased cancer detection, or improved survival among patients with some cancers.

Several factors could account for the differences in survey- and registry-based estimates of cancer prevalence. Some degree of underascertainment of cancer by survey is expected because the NHIS includes only the noninstitutional household population. Individuals seriously ill with cancer might not be included in the NHIS because they reside in hospices, nursing homes, or hospitals. Others might have refused the interview because of their poor health.

The NHIS provides an estimate of cancer prevalence based on individuals' self-reports and, therefore, would be expected to be less accurate than cancer registries that rely on clinically documented cancer diagnoses. The NHIS relies on accounts of diagnoses that may have occurred 30 or more years ago; while a diagnosis of cancer is likely a very salient event, evidence from the survey research literature suggests that the accuracy of recall declines markedly with time (6,7). Misunderstanding of the survey question might also explain some of the underreporting. Individuals were asked to report whether a medical doctor had ever told them that they had cancer; however, some may have failed to report their history of cancer if they considered themselves cured of the disease. Others may not have reported cancer to shorten the NHIS interview and to avoid further questions. The reluctance

to report socially undesirable behaviors and conditions in surveys has been well documented, and some may have failed to report cancer because of social stigma (7,8). Certain cancers that may be subject to stigma (e.g., colorectal cancer among men and women and lung cancer among men) were prone to underreporting. A similar pattern of underreporting by cancer site was evident in analyses of the 1987 NHIS (5).

Whatever the mechanism, underascertainment or underreporting appears to be mainly a problem among men. To the extent that there may be a geographic variation in cancer incidence or survival rates, the U.S. sample may differ from the population represented in the Connecticut registry. However, geographic variation in cancer incidence does not explain the difference in prevalence as ascertained by survey and registry. During 1990 through 1994, the total cancer incidence rate in Connecticut was lower than that for the nation for males but not for females (9).

Other cancers (e.g., female genital cancers) were overreported. This overreporting could be explained if some women confused positive screening tests with a diagnosis of cancer. There is evidence of misreporting cancer site, especially among women. This could be explained in part if individuals with recurrent cancer reported the site of a recurrent cancer when they were asked about the site of cancer that was first diagnosed.

Long-term cancer survivors are likely to be those who were diagnosed at an early stage of the disease and who experienced successful treatment. According to the 1992 NHIS, most cancer survivors have lived 5 or more years following their diagnosis and more than one third rated their health as excellent or good. Even though cancer survivors may not be similar to all who have undergone treatment for cancer, it is of interest to assess aspects of their care experience.

The majority of cancer survivors (diagnosed within the last 10 years) had received a second or multiple opinions regarding their treatment. Widely publicized treatment options for breast cancer may account for higher rates of second opinions among women diagnosed with breast cancer. Hispanics are less likely to have health insurance and other resources to pay for care; therefore, it is surprising to find a threefold greater likelihood of use of a second opinion among Hispanics. Health insurance status at the time of di-

agnosis is likely a strong predictor of use of a second opinion, but this variable was not available for analysis. Perhaps the practice of seeking opinions from different doctors was not well understood (e.g., the question asked whether more than one opinion was sought, without specifying that it was the opinions of the doctors that were germane).

Cancer patients may have multiple treatment options to consider. Educational materials can provide information about cancer, its treatment, and community resources available to aid individuals and their families. Nearly 60% of cancer survivors were given written patient information materials by their providers. Being under age 65 years at diagnosis was predictive of receipt of educational materials. It is not clear whether providers are more likely to give information to younger patients or whether younger patients are more likely to request information (or perhaps recall receiving information). Other research (10) suggests that seeking information from doctors and nurses declines with age. Cancer organizations, such as the American Cancer Society and the National Cancer Institute, offer a wealth of information; however, according to the NHIS, they appear to be underutilized, with only 11% of cancer survivors contacting them following their diagnosis.

Cancer takes a psychologic as well as a physical toll, and it is therefore surprising that fewer than 15% of cancer survivors had received counseling or had participated in support groups. Most survivors said that they did not need or desire counseling or support services, but nearly one in 10 who did not receive these services did not know that they were available. Other research also shows relatively low use of formal support groups. In a survey of individuals treated at cancer facilities throughout Texas, only 23% belonged to a support group. Most respondents had not been asked to join such a group (11).

Clinical trials and other research programs often provide the best possible care for patients with certain types of cancer. Only 5% of cancer survivors reported having participated in research studies. There are few recent estimates of involvement in cancer research to serve as a comparison, but about 2% of adult cancer patients enroll in National Cancer Institute-sponsored cooperative group clinical trials (12). Patients may also participate in other government-sponsored (e.g., De-

partment of Defense or Department of Veterans Affairs) or privately sponsored (e.g., pharmaceutical or biotechnology companies) cancer research.

A diagnosis of cancer can limit access to health and life insurance because of pre-existing condition clauses in policies. Furthermore, individuals with private health insurance coverage can experience premium rate increases or can be dropped from plans. The U.S. Congress tried to remedy this problem in 1996, enacting the Health Insurance Portability and Accountability Act (Kennedy-Kassebaum Act) to improve the portability and continuity of health insurance coverage in private insurance markets and among employer-sponsored group health plans. The Act limits the ability of insurers to deny or discontinue coverage because of pre-existing conditions such as cancer. The increased cost of the premiums for portable insurance products and difficulties in implementing the law, however, have limited the value of the new protections for consumers (13).

In 1992, roughly one in nine cancer survivors reported that they had been denied health or life insurance coverage because of cancer and just over one in 20 cancer survivors with private health insurance reported that their health insurance coverage changed because of cancer following their diagnosis.

Nearly one in five cancer survivors employed around the time of their diagnosis reported work-related problems stemming from their cancer diagnosis. Most of these related to "job-lock," an inability to change jobs because of a fear of loss of insurance coverage or medical privacy issues. This estimate is much lower than other surveys would suggest. In a 1992 survey of cancer patients treated at an acute-care, comprehensive cancer center in Houston, TX, the majority (58%) said that they would not leave their current position because of health insurance (14). This survey's focus was discrimination in employment, and those with problems may have been more likely to participate. Patients treated at the comprehensive cancer center may also have experienced more problems than those represented in the survey because they had more severe disease.

According to the 1992 NHIS, some cancer survivors experience workplace discrimination—4% reported having been fired or laid off from their job because of their cancer, and 5% said that they faced

on-the-job problems from their employer or supervisor directly related to their cancer. Discriminatory practices have been reported more often in other surveys (14,15).

In summary, the 1992 NHIS provides valuable information on the medical care experience and social implications of a diagnosis of cancer. While there appears to be some degree of underreporting of cancer relative to estimates from cancer registry data, the 1992 NHIS is one of the few sources of information about cancer survivorship from a nationally representative sample of U.S. households. Other information on cancer survivorship is forthcoming from two large studies being conducted by the American Cancer Society (16).

REFERENCES

- (1) Benson V, Marano MA. Current estimates from the National Health Interview Survey, 1992. Hyattsville (MD): National Center for Health Statistics. Vital Health Stat 10 (189), 1994.
- (2) National Center for Health Statistics. 1992 National Health Interview Survey [database on CDROM]. CD-ROM Series 10, No. 6. SETS Version 122a. Hyattsville (MD): National Center for Health Statistics; 1995.
- (3) Feldman AR, Kessler L, Myers MH, Naughton MD. The prevalence of cancer: estimates based on the Connecticut Tumor Registry. *N Engl J Med* 1986;315:1394-7.
- (4) StataCorp. Stata Statistical Software: release 6.0. College Station (TX): StataCorp; 1999.
- (5) Byrne J, Kessler LG, Devesa SS. The prevalence of cancer among adults in the United States: 1987. *Cancer* 1992;69:2154-9.
- (6) Rubin DC, editor. *Autobiographical memory*. Cambridge (U.K.): Cambridge University Press; 1986.
- (7) Groves RM. The respondent as a source of measurement error, chapter 9. In: *Survey errors and survey costs*. New York (NY): John Wiley & Sons; 1989. p. 407-48.
- (8) Eisenhower D, Mathiowetz NA, Morganstein D. Recall error: sources and bias reduction techniques. In: Biemer PP, Groves RM, Lyberg LE, Mathiowetz NA, Sudman S, editors. *Measurement errors in surveys*. New York (NY): John Wiley & Sons; 1991. p. 127-44.
- (9) Ries LA, Kosary CL, Hankey BF, Miller BA, Hargis A, Edwards BK, editors. *SEER cancer statistics review, 1973-1994*. Bethesda (MD): National Institutes of Health, National Cancer Institute; 1997 Report No.: DHHS Publ No. (NIH)97-2789.
- (10) Turk-Charles S, Meyerowitz BE, Gatz M. Age differences in information-seeking among cancer patients. *Int J Aging Human Devel* 1997; 45:85-98.
- (11) Guidry JJ, Aday LA, Zhang D, Winn RJ. The role of informal and formal social support networks for patients with cancer. *Cancer Pract* 1997;5:241-6.
- (12) National Cancer Institute. *The nation's investment in cancer research: a budget proposal for Fiscal Year 1999*. Bethesda (MD): National Cancer Institute; 1997.
- (13) U.S. General Accounting Office. *The Health Insurance Portability and Accountability Act of 1996: early implementation concerns*. GAO/HEHS-97-200R, Washington (DC): GAO; September 2, 1997.
- (14) Rothstein MA, Kennedy K, Ritchie KJ, Pyle K. Are cancer patients subject to employment discrimination? *Oncology (Huntingt)* 1995;9: 1303-6; discussion 1311-2, 1315.
- (15) Wingard JR, Curbow B, Baker F, Piantadosi S. Health, functional status, and employment of adult survivors of bone marrow transplantation. *Ann Intern Med* 1991;114: 113-8.
- (16) Hewitt M, Simone J, editors. *Institute of Medicine. Ensuring quality cancer care*. Washington (DC): National Academy Press; 1999.
- (17) *International Classification of Diseases, 9th revision. Clinical modification, 1993*. Salt Lake City (UT): Med-Index Publications; 1993.

NOTES

¹Questions about cancer treatment and the experience of cancer survivors were limited to those respondents who reported that they had been diagnosed with cancer within the last 10 years. (There were 656 respondents with cancer [excluding skin cancer other than melanoma].)

²Noncentral city MSAs often include the "urban fringe" or suburban areas outside the central cities.

The analysis, opinions and assertions contained herein are those of the author and are not to be construed as reflecting the views or position of the National Academy of Sciences, the Institute of Medicine, or the National Research Council.

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